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Nonpsychotic, nonparaphilic self-amputation and the internet

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Abstract

The literature suggests that self-amputation is an outgrowth of either psychosis or paraphilia. In the case we present, the patient was neither psychotic at the time of amputation, nor did he ascribe a sexual motivation for his act. Instead, he had a long-standing idea that being an amputee was a critical aspect of his identity. The patient used the internet to research the method for his amputation and sought support from individuals with the same desire via e-mail, web sites, and Usenet news groups.

1. Introduction

Most articles describe self-amputation as when psychotic individuals act out bizarre delusions. Schlozman [1] reviewed the literature from 1966 to 1998 and found 11 cases of upper extremity amputation. He contributed 2 more cases of his own. All 13 patients were experiencing psychosis. In most of the patients, amputation was the result of guilty and/or religious delusions. Suicidal intent was a feature in only a few. All patients had their limbs reattached.

Money et al [2] described the first modern case histories of 2 nonpsychotic patients who desired to become amputees. They used the term *apotemnophilia* to describe this condition. The patients had intense and intrusive thoughts to amputate a lower extremity. These thoughts were related to sexual fantasies and sexual arousal. Apotemnophilia is differentiated from *acrotomophilia*, which refers to sexual attraction toward amputees. Money et al noted that their patients described both apotemnophilic and acrotomophilic tendencies. Money et al followed their patients for 3 to 4 years. Although neither effected an amputation, both continued to desire it despite treatment with psychotherapy.

In considering nonparaphilic explanations, Money et al suggested that apotemnophilia might have some commonality with Munchausen syndrome. Like patients with Munchausen syndrome, patients with apotemnophilia seek medical services. However, patients with Munchausen syndrome repeatedly induce symptoms for the sake of being a perpetual patient. In contrast, patients with apotemnophilia appear satisfied with a singular amputation and usually do not repeat self-injury.

Everaerd [3] reported a case of apotemnophilia. At the age of 8 years, his patient developed an attraction to people missing a leg. At the age of 10 years, he developed a desire to have peg leg himself. He felt that those with a peg leg were happier. Later in life, the patient developed chronic suicidal ideation, feeling defeated by the control these ideas had over him. Earlier, this patient experienced sexual arousal associated with the idea of amputation. Later, these feelings took on a more general tone and the patient felt that he could only be complete if he were an amputee.

Bruno [4] described 2 cases, 1 of apotemnophilia and the other of acrotomophilia. He suggested a common psychological model to describe these disorders: factitious disability disorder. He advanced the idea that the common link between these cases is a desire to be disabled or to be in the company of people with disability.

Elliot [5] suggested that apotemnophilia may not be as rare in nonpsychotic individuals as earlier believed. He described the many web sites, chat rooms, and Listserv

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areas on the internet where individuals with these conditions have extensive communication. On one Listserv message system, Elliot found 1400 subscribers to an amputation "wannabe" group. He suggested that the desire to become an amputee or to have sex with an amputee is likely to be underreported because of the stigma related to such thoughts. Elliot also referred to 2 recent cases where a Scottish surgeon performed 2 above-the-knee amputations for patients who had a lifelong desire to be amputees [6].

We contribute to the literature the case of a patient who carried out self-amputation. This patient was not psychotic and did not experience sexual fantasies or sexual arousal related to becoming an amputee. The patient obtained information on how to carry out the amputation from the internet.

2. Identifying information

Patient A (PA) initially presented for treatment as a divorced, early 50s (years old), male-to-female transsexual. Patient A had not had sex reassignment surgery but had been taking feminizing hormones since he was 51 years old and had been living as a woman for 4 years. In addition to his transsexual status, PA envisioned a *true self* as an amputee. Patient A had considered numerous methods of removing his left arm and left leg but had not yet acted on this desire when presenting the first time for treatment.

3. History

Patient A was born an only child and was raised by schoolteacher parents who were in their early 30s (mother) and late 30s (father) at the time of his birth. Patient A reported physical and psychological abuse by his mother and neglect by his father.

Patient A was about 10 or 11 years old when he began developing a fascination with disability and amputation. Patient A remembers several influences. First, he had a classmate who had one leg, managed ably with the use of crutches. Next, he enjoyed a maternal relationship with the mother of his best friend. This older woman limped as a result of polio. Patient A had stated, "I had been lamenting my immunization against polio when I was 10 in the mid-1950s." Finally, he remembers a *Life* magazine article that pictured children in polio wards smiling and playing ball. All this led PA to feel that his mother may have cared for him more if he had a disability. Before long, the patient secretly started crossdressing, pulling a leg into his pants, and using crutches to walk. These behaviors persisted into adulthood. Patient A remembers that feelings of being *unwanted* and *unloved* as a child occurred as a result of the belief that his mother would have preferred a daughter to a son. In early puberty, PA began wishing he were a girl.

Abused at home by parents who taught him high school, he avoided his studies, performed marginally in his course work, and was frequently disciplined for minor offenses such as passing notes or talking disruptively in class.

Patient A was drafted into the navy and graduated from officer candidate school. In total, he served for more than 5 years. His military career was cut short by diabetes, asthma, and an ankle injury. Honorably discharged, he was placed on disability retirement.

His first postmilitary job was in a prosthetics laboratory. A mid-level manager, he used his spare time experimenting with wearing prosthetic devices and eventually designed a prosthesis for himself. During this time, PA also obtained his bachelor's degree and began his studies toward a master's degree in history.

Patient A married when he was in the military. He was sexually active, fathering 6 children. All told, PA was married a little more than 20 years. The marriage ended in divorce after his spouse discovered him crossdressing and pretending to be an amputee.

4. Treatment course

Patient A was admitted to our inpatient psychiatry unit after attempting to suffocate himself with a plastic bag. Panicking, he aborted the attempt deciding that "this is not an easy way to die." Patient A reported the reason for the suicide attempt was that, "making the transition to living as a woman did not cause any abatement of the incessant thoughts about being/becoming an amputee. There was also rage directed toward my mother and ex-spouse. My mother because perhaps, without her abuse, I might have had a 'normal' life and toward my 'ex' because she had been making it so hard for my youngest [child] to spend any time with me."

At admission, PA was articulate, affable, and clearly intelligent. He was effeminate and appeared comfortable living life as a woman. He was fully oriented and thoroughly grounded in reality. He was also perfectly euthymic.

After an uneventful hospitalization targeted at stabilizing a suicidal crisis, initiating psychotherapy, and arranging for follow-up care, PA was discharged to outpatient care with a psychiatrist and a psychologist. Despite close professional attention, PA made his first attempt at amputation shortly after discharge. Patient A placed an ace bandage and 2 pipe clamps over his left leg. He tightened the clamps over the next several hours. The pain became unbearable and he presented to the emergency department having caused swelling but not irreparable damage.

Patient A was hospitalized a second time on the inpatient psychiatry service. Again, he was free from psychosis. This time, PA was entirely without suicidal ideation. Again, he received intensive inpatient psychotherapy.

Initially, PA used a wheelchair for mobility because of the swelling in his legs. When the swelling receded enough to permit a transition to ambulation, PA refused to walk, complaining that his legs were "too weak." The staff noted that PA appeared to take comfort in being wheelchair bound.

At one point, PA acknowledged feeling "more authentic" and feminine when he was in the wheelchair.

After a lengthy hospitalization and verbal assurance from PA that he no longer intended to self-amputate, he was discharged to a residential psychiatric treatment program. Patient A continued with the same psychiatrist and psychologist for outpatient care.

Several months after discharge, PA presented to the emergency department after putting both lower extremities in support stockings and packing them in dry ice for 7 h. Severely frostbitten, PA had no pulses below either popliteal fossae. Patient A required bilateral above-the-knee amputations. Patient A had no surgical complications and his postsurgical recovery was unremarkable.

At the time of this third presentation, PA was not psychotic. Patient A calmly told the emergency department staff that he did this because "I want to be an amputee." When instructed on the life-threatening nature of the injuries, PA said, affirming a lack of suicidality, "I hope not to die."

After surgery, PA was transferred to a nursing home care unit located in the hospital. In therapy, PA revealed that he had been interacting on the internet in a news group designed for self-amputees. Through these online communications, PA deepened his motivation, developed the means, and finalized his determination to act on his desire.

Patient A was followed for 3 months after amputation. He never exhibited either doubt or depression about his act. Instead, PA frequently reported finally "feeling like a complete person." Patient A looked forward to his prosthetic legs and playing tennis in a wheelchair. The only regret PA verbalized was over the pain he endured secondary to the freezing itself. Patient A wished that voluntary surgical amputation could have been available to him. He applied for and eventually received disability income. According to PA, his Social Security disability benefit was due to being a bilateral, above-knee amputee. His Veterans Administration disability benefit was increased to 90% based on diabetic neuropathy in his hands, wrists, and elbows coupled with coronary artery disease. Patient A was granted an additional 10% on the basis of unemployability.

After the initial convalescence, PA moved to the West Coast, not planning to inform others of the true manner of his amputation. At the time of PA's relocation, he continued to dress like a woman and take female hormones. Patient A still planned to have sex reassignment surgery once he had saved enough money.

5. Follow-up

In follow-up contacts with PA 2 and 3 years after his amputation, he reported that he no longer desired to be a woman and had resumed living as a man. He reported being "happy" with his amputations. He was no longer in communication with the wannabe community (people wishing to be amputees) but had established connections with the "legitimate" amputee community. One reason for resuming his male role was to regain a father and grandfather role with his children. He also stated:

> The amputation desire came first and foremost. It was just that an avenue became available to do something about one of my obsessions [male-to-female transsexual] through "approved channels." Both were, as I now understand them, defense postures I took as a way to absent myself from situations in which I felt incompetent or threatened. One can fully transform oneself in becoming an amputee. The adoption of the desired characteristic is complete and without ambiguity. No matter how many hormones or other drugs I took or however much surgery I endured, I, as a biological male, could never really be a female, as I understand that label. Once I was an amputee, the thin shell that was my feminine presentation was seen more and more for the masquerade it was.

Patient A additionally stated that he felt complete as an amputee. He explained this by the following:

> "Completeness" in this context refers to having a sense of self that is well established in my own mind. It was not enough to have the labels that could appropriately be used to describe me (male, white, etc). Being an amputee, especially a DAK (double above-knee) is a rare distinguishing characteristic. It is something about me that is noticed, accords me certain accommodations and cannot be denied. Being [a female] did give me many of the same sorts of "feedback" notice, gestures or appreciation and interest as well as social courtesy. But, in my heart-of-hearts, [my female role] was someone I put on. PA, the amputee is something even I cannot take off and no one can take it from me in the way that [my female role] could be denied.

However, PA continued to have some self-amputation ideation shortly after he had made friends with a 4-limb amputee. This friendship led him to have new thoughts to freeze his left arm. He was hospitalized 1 year after his initial amputations for this new self-amputation ideation. He was treated with fluoxetine 60 mg daily, which appeared to have diminished but not eradicated his desire for further amputations.

6. Discussion

In reviewing the literature, there is little definitive agreement regarding the theoretical conceptualization of the desire to self-amputate and its diagnosis and treatment. Previous case studies of self-amputation [1,2,7-9] involve either psychosis or paraphilia. The self-amputation case presented here was certainly not a result of psychosis and apparently not a result of paraphilia. Instead, PA suffered from poor self-esteem and was aware of longing for what he perceived he lacked from his parents, affirmation and acceptance. At the time of the amputation, PA felt amputation would contribute to his femininity. Additional possible psychological explanations for self-amputation discussed in therapy by PA included the following: (1) to be disabled and demonstrate

a capacity to overcome adversity, (2) identification with a surrogate parental figure, (3) adopt a unique identity, and (4) to prevent himself from acting violently toward another or even more violently toward himself (suicide). Many different etiological hypotheses could be suggested from various theoretical perspectives; however, definitive explanations would be speculative in a single case review.

Diagnostically, this case presented a significant challenge. Borderline personality disorder (BPD) was considered as a diagnosis for our patient. Self-mutilating behavior is a key feature of BPD [10]. Self-amputation could be viewed as a form of self-mutilation, but it is not the typical type of mutilation shown by those with BPD. A Medline search (topics: BPD, amputate or amputation; 1968-2002) found no writings on self-amputation and BPD. More commonly, patients with BPD cut or burn themselves when dissociating, attempting suicide, or reaffirming the sense of being evil. However, our patient reported the amputation as a means of "being whole." Our patient did not report typical lifelong impulsive, affective, suicidal, and interpersonal instability or problems with overt anger related to BPD. Patient A did report feelings of emptiness and an identity disturbance before the amputations, which were directly related to feeling "unwhole" because he was not an amputee. Therefore, BPD does not fully or consistently describe these symptoms.

We also considered the diagnosis of body dysmorphic disorder. Our patient expressed feeling "incomplete" with intact limbs. A Scottish surgeon, Robert Smith, performed surgical amputations of 2 men, 1 in September 1997 and the other in April 1999 [6]. The surgeon believed that the patients he operated on felt incomplete with all their limbs. Each man received an above-the-knee amputation. The patients reported improvement in their lives after amputation and were, in the words of the surgeon, "delighted with their new state."

Body dysmorphic disorder is, in the language of the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*, "a preoccupation with a defect in appearance." In our case, the "defect in appearance" is the presence of 4 normal limbs. Patients feel that to be "complete," it is necessary for them to be without one or more limbs. A closely related condition is delusional disorder, somatic type. According to the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*, patients with this condition have delusions that they have some illness or physical defect. Common presentations include delusional preoccupation with the emission of odors (from the skin, mouth, vagina, or rectum) or infestation by parasites or the dysfunction of some body part (such as the large intestine) or that a particular body part is deformed. In body dysmorphic disorder, preoccupations do not usually reach a delusional threshold. In delusional disorder, they do. These diagnoses do not adequately describe the condition of our patient, as the preoccupation is not necessarily focused on a problem with the limb, but rather on not being "whole" with the limb.

Further studies and research are necessary to determine the prevalence of and whether it might be important classify this disorder, which may in turn determine treatment considerations. Treatment approaches could range from a wide range of recommendations. Individuals in the wannabe community and others such as Robert Smith believe that elective surgical amputation is a viable treatment option. They suggest that self-amputation is not dissimilar to sex reassignment surgery, now considered medically acceptable. They further argue that elective surgery not only relieves suffering but also provides a much safer option for desperate patients. This, of course, would open countless ethical scenarios. Not given the choice of voluntary surgical amputation, our patient carried out a life-threatening method to bring about his wish. Opponents of this view fear that mere acceptance of this condition as a medical disorder, let alone a surgical remedy, will increase its prevalence. More standard psychopharmacological and psychological interventions need to be considered in helping a patient overcome intrusive thoughts. However, these were not effective with our patient. Further studies are necessary to determine appropriate treatment approaches in these unusual cases.

Finally, the internet is a powerful information resource. More than 50% of adults have personal computers. At least 25% of all United States households have internet access. The patient we presented used chat rooms (news group) on the internet. This had a normalizing and validating effect on otherwise pathological and relatively rare ideations. It is likely that without the internet, our patient may never have met someone with similar ideas. In addition, the internet helped provide a blueprint for self-amputation. Without the internet, our patient may never have conceived, let alone used a method to bring about, self-amputation. We anticipate that increasing internet access will lead to more cases of self-amputation.

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